Instruction and Information about PPSv2 by Category of Questions

Questions about "General Use of PPS Tool"

1. ***Are there references for the use of PPS?***

   Answer: Yes there are many published studies as seen in the references at the end of this document.(1-40)

2. ***What is the difference between PPS and PPSv2?***

   - **Answer**: The official one in use now is PPSv2. It is almost exactly the same with only changes being replacement of ditto marks with appropriate phrases and inclusion of an 'instructions for use' [as we became aware over the past few years that several programs were using it incorrectly - for example, some were incorrectly adding up scores for each category and averaging them to calculate a PPS]. We have checked with our stats analyst who says this does not mean reliability or validation testing needs to be repeated.

3. ***What levels of staff are using this tool - nurses, occupational therapists, pastoral workers?***

   - **Answer**: PPSv2 can be used by many palliative workers – nurses, physicians, RT, PT, OT, dieticians, pastoral, volunteers, etc

4. ***Have family members who are caring for their loved ones at home ever been educated on the use of the PPS or in your opinion would it even be useful?***

   - **Answer**: PPS is used mainly by professional staff. However, there are some patients or family members who are very involved and meticulous in their care and what is being assessed and planned. For these occasional times, sharing PPS has been helpful and appreciated.

5. ***How often do you recommend the use of this tool in a home care palliative care setting where there are possibly various levels of caregivers in the home? Daily visits?***

   - **Answer**: In general, PPS should be rated on each home nursing visit which of course may vary from daily to weekly or less. In our Palliative Care Unit, it is done each day or at anytime the patients' condition changes.

6. ***Should PPS be calculated from 'observed' function or 'capable' of function?***

   a. "One area which could affect reliability in use of PPS in residential settings where patients have less opportunity for independent functioning, regardless of whether they are capable of such activity" (Head and Ritchie)(33).

   b. Thus, raters should be instructed to ask appropriate questions about ***what the patients is able to do***, rather than formulating the rating solely from observation

   - ***Case Example:***
     66 year old female with breast cancer. There is mets to lung and bone and now progressing to her brain. She enjoys visits with her daughter where they spend time putting together puzzles. It frustrates her to not be able to get out of bed, but any weight on her femur may cause a fracture. Her daughter brings in her favorite foods pureed. Her O2 sats drop to mid 70's when she tries to eat solid food. CNA visits are scheduled 3 times a week because she has a purple area on her coccyx and family is unable to get her to the shower.

     Answer: You note she can't get out of bed since that may cause pain and possible fracture. PPS is determined not by what the patient "is doing" but by what patient "could do". In other words, the caution about being in bed is not her physical limit but a practical limit. Thus, her PPS would be somewhere at 40% or higher depending on what amount of assistance she would need to sit on the bed or move to commode chair. If 'extensive' [eg 2 person transfer then PPS 40%; if she could easily do on

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her own, then PPS 60%]

7. ***When I read horizontally to find the best fit, can I choose a level that is higher, or must it always be a lower level?***
That is, the instructions state that PPS level is determined by reading left to right to find a 'best horizontal fit' Eg. When the ambulation is on PPS 50%, I read horizontally right to activity and can choose from 50% or lower, but no more from 50% or higher)? So right- and downwards but not right and down- or upwards to find the best horizontal fit?

Answer: You may go up or down. When looking horizontally, you may find that the current level, or one below, *or one above* is actually the "best fit". The leftward precedence is a guideline to viewing it, but then judgment as to whether the level for this patient should be higher or lower. In general, the leftward columns are 'stronger' and that is why one looks at those first.

8. ***Reply points to an email regarding use of PPS*:**

Answer: 1. As you are fully aware, all scales are subject to **individual variation**. Several show differences between nurses and physicians, nurses and caregivers, caregivers themselves. So reliability and validity testing are ways of trying to see if they are generally helpful. As such, current testing for PPS has been professional reliability and some degrees of validation.

2. Although intended as a professional tool, there are **many families, and some patients, who have used PPS**. I just had an email from a husband in Ontario who wanted some information on prognosis. He had already assigned her a PPS 40% as he had access to the tool, and then verbally described her situation which my conclusion would also be 40%. My anecdotal experience is that family are often quite accurate.

3. What would be good is a study to compare family vs nurse/MD ratings; your query certainly makes me think along this line. Family would need to be approached with caution as for some the categorical nature of the tool can be off-putting.

9. ***PPS Scoring Can NOT be summed***
However, my concern with your suggested approach is that the **summation** of individual items and subsequent overall calculation is **not the way PPS is used**. Indeed, several people were incorrectly using this over the years by summing each PPS and making an average rating. Others were choosing the highest or the lowest of the scores. The instructions are a 'best horizontal fit' which is an overall clinical judgment and I don't see that there can be very different ways of using a tool and having it meaningful. For these reasons, I would not approve of using PPS in a different way.

10. ***In how many languages is PPS available?***

- It is translated into at least 9 five languages at present
- English, French, Japanese, German, Thai, Arabic, Spanish, Portuguese and Dutch

Questions about "Disease"

11. What are the definitions of 'some evidence' of disease, 'significant' and 'extensive' disease? Is this measured purely in terms of pathology or are the psychological impact etc considered?

- **Answer**: 'Some,' 'significant,' and 'extensive' disease refer to both physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease.
- As this is a physical functional scale, psychological impact is not considered in the determination. It is what a person is capable of doing, not what they choose to do. For example, anxiety, sadness or

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demoralization may result in the patient sitting at home a lot, but unless they actually require some assistance to get up (PPS 50% or 60%), the PPS would be higher.

12. ***Case Example:***
Diagnosed with Ca Breast with metastasis to lymphadenopathy and pericardial effusion. History of: Mental retardation, Turner's Syndrome since young. Self care done by family as not able to perform it herself. Eating well and walking normally.

    Answer: There is significant/extensive disease since a pericardial effusion is a significant or even serious complication of the breast cancer, but she can walk 'normally' [not sure what that means] so PPS is around PPS 70%, 60% or 50%. Since self-care must be done by family, this would move her to the lower one of PPS 50% as 'considerable help' is needed. It might have even been PPS 40% for self-care but the fact she walks well means that level is too low. The fact of mental retardation does not affect the status as this is developmental disability and not due to the cancer. If she became confused or delirious from sepsis or drug effects then that column is used but not for the ongoing disability itself.

    So I think her performance status is PPS 50%. It is the disease and pericardial effusion that 'pulls' the level downwards and the ability to walk normally that pulls the level upwards.

Questions about "Ambulation"

13. Often we see people at diagnosis who are fully ambulatory, normal activity and work but have extensive disease where do they fit in?

- **Answer**: PPS is determined by a "best fit" recognizing, as noted here, that some categories do not line up well. This necessitates a clinical judgment decision. In this case, the aspect of full ambulatory and normal activity indicates quite a high PPS and the 'extensive disease' is clinically less relevant, at least for the moment. A PPS 80% would be appropriate designation.

14. **Example 1:** A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

15. People who are unable to work because chemotherapy is demanding, but only have some evidence of disease, how do I score them?

- **Answer**: PPS should be determined by the actual ability to do something, not by desire, or lack of. In this case, it is not clear what 'demanding' means. If the patient is so physically sick or fatigued that they cannot work, then the PPS is rated accordingly - PPS 70% would be appropriate if can do some work at home, but could be reduced to PPS 50% if they were so sick that they required actual assistance at home.

16. People who are unable to do most activities due to poor family support or depression but have only some evidence of disease, where do they fit in?

- **Answer**: PPS should be determined by the actual ability to do something, not by desire, or lack of. If the patient is clinically depressed and thus not getting up much, but is in fact able to do so, then the PPS level would be higher at 70% or 80% since in this case there is little evident primary disease impact.
- The same would apply to family support. Little or no assistance by family or friends to get dressed or out of bed will clearly impact quality of care, and may eventually add to physical decline, but if the patient could be up with adequate assistance, then PPS would be accordingly higher.

17. When a patient's mobility is limited because she/he has a fracture in a weight bearing bone, will it translate into the same score as if the inactivity was due to extreme weakness and fatigue?

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- **Answer**: Yes, the PPS will be lower as the patient functionally is less able to activate. PPS indicates functional capacity, not the diagnosis or reason for any decline. If in full traction, PPS would likely be PPS 40% since he or she is bed-bound but can do some self-care. If in a cast and using a walker or crutches, PPS might be 50%. It would also be expected that, all things being the same, the PPS will increase shortly as mobilization improves.

18. ***We seem stuck on one particular point that relates to the definition of "totally bed-bound".***
Some of us feel that if any assistance is required to get a patient out of bed then that patient is "totally bedbound". Others feel that the VHS instructions suggest that requiring assistance to get out of bed does not render one to be "totally bedbound", so they may have a PPS score of > 30.

    Answer: The concept of "total" bed-bound relates to actual ability of the patient to do anything by himself/herself including their own self-care. At PPS 30%, the patient is completely unable to turn, sit up or get out of bed as well as unable to raise food to the mouth or do any toileting/grooming. So this is a physical inability usually related to weakness or possibly paralysis. This inability is not due to depression or that the person chooses not to get up but rather that they cannot.

    However, staff may and often do have the patient moved out of bed either with 1-2 staff or with lift equipment. If the patient is unable to assist in this, as noted above, then PPS=30% since the person would be "bed-bound" unless physically moved. If the patient can sit on the edge of the bed, perhaps even attempt to stand or turn to sit, but needs 1-2 person transfer assist or would clearly fall, then PPS would be 40% if 'extensive' assist or 50% if 'considerable' assist. The decision about PPS 30% then is whether or not the patient can do anything of their own accord, especially in bed. A PPS 30% can be moved out of bed but only by the physical efforts of staff.

    In many ways, "totally bed-bound really means that the patient is so affected by their condition that they are completely unable to assist in getting out themselves of bed" but with one addition. The issue is not only 'bed status' so to speak but the item is also in the column 'self-care.' So it is better to say "... completely unable to assist in getting out themselves of bed ***and unable to do any self-care***". The ADL Hierarchy Scale by Morris et al (Journal of Gerontology: Medical Sciences 1999. 54A(11):M546-M553) that is within the InterRAI assessment tools would match PPS 30% as #6 "total dependence" if that helps or if you use it.

19. Case Example:
94 year old man who has diagnosis of AFTT. There is no family that is local and a patient care giver comes in for housekeeping and meal prep. At her last visit she called hospice because she found him just sitting on the couch scooting from end to end. There was no recognition of her and he yelled at her to get out of his house. She got him calmed and pivot-transferred him to the wheelchair. Yesterday he had been able to self transfer. She fixed him lunch and he stuffed his sandwich into his glass of milk. After she showed him his spoon, he was able to feed himself soup but drooled most of it out.

Answer: If by scooting you mean he can move himself from one end of the couch to the other and back, then he has some self abilities. He needed assistance to pivot into wheelchair. This sounds like PPS 50% or 40% depending on how much he can actually do on his own. Does he later get off the couch and go to bed on his own? (if so, then PPS would be higher at 50-60%). Although angry and difficulty with food, he does feed himself.

Questions about "Self-Care"

20. **Example 2:** A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%.

Answer: Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

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21. **Example 3:** However, if the patient in the above example was paraplegic and bed bound but still able to do some self-care such as feed himself/herself, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

22. ***Case Example:***
The patient is totally bed bound at 30%, activity 30%, but self care is viewed to be 50%, intake 70% and consciousness is 70%. Can we go from 30% back up to say 50%?

Answer: PPS 30% means the combination of total bed bound, no activity AND no self-care at all (ie. Cannot lift his arms, cannot help to turn in bed, cannot feed himself or brush teeth). But you indicate here his self-care is 50% and if this is correct, then he cannot be PPS 30%. If he requires extensive assistance in bed to turn, eat, etc then PPS would be 40% and needs 2-person help; if he can do a little more, then PPS 50% with perhaps 1 or 2 person help to sit, commode, etc.

PPS is always the "best fit" and you work from the left side first. In this case, it is the amount of self-care required that determines whether30, 40 or 50%.

Questions about "Coma or Semi-conscious"

23. ***How does one assign a PPS on a comatose patient?***
Case Example: A post-stroke patient is in the ICU. He is now off ventilation but remains comatose. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400ccs is put in and 300 ccs comes back. On occasion, he responds minimally to stimulation.

Answer: This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which could be seen as the equivalent of 'sips only'. Thus his PPS would be decreased to PPS 20%. If there is a decision to stop tube feeding, then would be construed as mouth care only and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

Questions about "Dementia"

24. Can PPSv2 be used with dementia patients?

- **Answer**: In general, the answer is yes. PPSv2 is a functional performance scale which primarily focuses on ambulation, activity and self-care. Particularly in advanced stages of Alzheimer's disease, the patient fits quite well into such levels as PPS 50% through PPS 10%.
    a. In the reference article by Doberman et al, PPS was demonstrated as better than several current tools in survival prediction.(29)
- The cognitive aspects of 'dementia' are not well differentiated with PPSv2 in that cognitive decline may occur while 'ambulation' is still quite good. However, in terms of activity and evidence of disease in the second column, PPS 70% and PPS 80% indicate difficulty with normal work or job function which in the case of Alzheimer's is attributed to mental status challenges from the disease rather than actual physical capacity.
- The fifth column 'Conscious Level' was mainly intended to separate full 'alertness' from reduced levels such as drowsiness, obtundation and coma. It does recognize confusion but primarily as it relates to these factors and possible delirium rather than dementia where full consciousness is present, at least at higher PPS levels.
- As with all diseases, PPS is a horizontal 'best fit' and judgment is always required.

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- Case example:

    a. Ms. Jones is a 75 year old woman who has had increasing forgetfulness over the last 3 years. She does self-care with her husband observing her. Sometimes he has to help her. She no longer drives but can walk to the grocery store 3 blocks away in a straight line by herself. She requires a list, however, of what she is to purchase and carries a label with her name, address and her husband's name to give to someone if she gets lost which has not happened so far. She generally is up during the day and sleeps most of the night. She used to read and knit at night but no longer does so, and will watch television, although she does not always remember what the content is. Meal preparation is done by her husband preparing the ingredients and her cooking the meal. She generally will eat a full meal but recently requires coaxing on occasion.

    b. **Answer**: [PPS is 60% in each of the five categories]

25. Case Example:

72 year old male with dx of Alzheimer's Dementia. His constant pacing hinders his PO intake as staff can't get him to sit at the table to eat. He can eat finger foods by himself. Often, he is found urinating in other areas than the BR. He is disoriented to time, place and person but will answer to his name. Sometimes he becomes aggressive when staff try to bathe him. He has no interest in personal hygiene. He is unable to provide own ADLs and staff must anticipate/provide all needs.

Answer: It appears that he is able to walk on this own as you note he is 'found urinating in other rooms'. If that is correct, then his PPS has to be at least PPS 50% or PPS 60%. You note he can't do ADLs and only finger foods so this would mean he needs "considerable assistance" and thus PPS 50% would be a reasonable level for him

26. Case Example:

88 year old man with dementia. The staff at the assisted living facility get him up each day with max assist of 2. He loves to watch the birds out the window and could sit there for hours. He will eat 100 % of his meal, but his favorite PCG has to be there or he won't eat at all. He is incontinent of both bowel and bladder and today his case manager saw him leaning to the left and had to prop him with pillows

Answer: With need of 2 person lift all the time, PPS is then down to about PPS 40%. Although confused and incontinent, he is able to eat well what is given which does fit with PPS 40% as well.

Questions about "Intake"

27. How is the "Intake" domain scored for patients whose primary or total intake is via feeding tube?

- **Answer**: PPSv2 is used by a 'best horizontal fit' of the 5 domains. As such, there are times where one domain such as intake is difficult to interpret and a G-tube or JPEG makes this challenging. Two suggestions may assist in decision making.
- The primary process is that if the other 4 domains seem clear at one PPS level, then that is likely the best-fit irregardless of intake. This is logical since the provision of some nutrition at any level becomes a non-distinguishing factor.
- The second consideration is the somewhat common observation that the tolerability and the volume of fluid given via parenteral tubes usually decreases with overall decline and closeness to death. For example, an ALS patient earlier in disease may tolerate 500-1,000 ml at one time but later in the course can only tolerate 300 ml or 100 ml. This is also seen in advanced cancer patients.

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28. ***How would I categorize a pt's PPS when the person's disease is causing an obstruction rendering the person NPO, yet is receiving nutrition per TPN?***
Case Example: Would I be correct in rating the person a 70% if she had full ambulation; significant disease with her localized ovarian cancer causing a bowel obstruction not allowing her to do her work, but could do hobbies; was able to do full self care including managing her TPN; was NPO; and had full conscious level?

Answer: Yes, the PPS would be correct at PPS 70%. Although nutrition is via TPN and technically not "intake" in the usual meaning of the word, it is anticipated that sufficient nutrients are being provided to approximately equate with being able to actually eat. This also fits with the general instructions that one use a 'best fit' and that not all horizontal factors must line up exactly.

29. ***How does one assign a PPS on a comatose patient with a NGT?***
Case Example: A post-stroke patient is in the ICU. He is now off ventilation but remains comatose. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400ccs is put in and 300 ccs comes back. On occasion, he responds minimally to stimulation.

Answer: This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which could be seen as the equivalent of 'sips only'. Thus his PPS would be decreased to PPS 20%. If there is a decision to stop tube feeding, then would be construed as mouth care only and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

30. ***Case Example***
45 year old female with cardiomyopathy. Her case manager reported that she was unable to get her out of bed today and her O2 sats had dropped from 92% on RA to 68%. She started her on O2. B/P was 70/38. The CNA reported that she had to give her a bed bath today and tried to feed her but she only drank a few sips of juice with use of a syringe and fell asleep. CM called family with update and urged them to come to the bedside.

Answer: Unable to get out of bed places PPS lower. CNA gives a bed bath but unclear if she is able to turn or help in any way. If she cannot do anything, then PPS is 30%. But she is drowsy, only few sips and falls asleep. If this is persistent and more than just fatigue, then PPS may be down at 20%, which seems the case since the worker called family to attend.

Questions about "Children"

31. ***Can PPS be used in the pediatric population?***

- **Answer**: There is no solid data regarding PPS and children. Clinically, we have used this in some children who are a little older and previously ambulatory, but it is not likely of value for infants.
- One would need to substitute "job/work" for school or usual activities, but otherwise most other factors are anecdotally reasonable. A draft of PPS-Ped-Child is under development

Questions about "Non-Palliative"

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32. ***Can PPS be used for "non-palliative" patients?***

Case Example: A post-stroke patient is in the ICU. He is now off ventilation but remains comatose. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400ccs is put in and 300 ccs comes back. On occasion, he responds minimally to stimulation.

Answer: This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which could be seen as the equivalent of 'sips only'. Thus his PPS would be decreased to PPS 20%. If there is a decision to stop tube feeding, then would be construed as mouth care only and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

The above case illustrates that PPS can be used for "non-palliative" patients. In this case, there was initial hope that he would improve and regain consciousness, possibly even to mobilize again. The physicians did not like nurses using PPS due to the word "palliative". Since PPS is a functional or performance assessment tool, its use does not need to be restricted to already designated palliative or hospice patients. One could "blur" or cover-up the word palliative in these circumstances to provide more ease in its use. Indeed, at the Maharaj Nakorn hospital in Chiang Mai, Thailand, PPS is recorded on every patient or every ward every day and thus includes, surgical, neonatal, oncology, ICU, CCU, ER, etc wards.

33. Can PPS be used in the pediatric population?

- **Answer**: There is no solid data regarding PPS and children. Clinically, we have used this in some children who are a little older and previously ambulatory, but it is not likely of value for infants.
- One would need to substitute "job/work" for school or usual activities, but otherwise most other factors are anecdotally reasonable. A draft of PPS-Ped-Child is under development using age adjusted paramaters

34. ***Case: a client has cancer, but also had a debilitating CVA- we questioned how the PPS would be validated in this case. Would it be a true reflection of client status? CVA vs Ca ?***

Answer: Good question. Indeed it is challenging. No tool can deal with every situation. If his stroke is old, and he has lived for some time this way, then PPS would reflect other changes or new types of decline due to cancer - for example, going from needing some assistance, to total care, etc. in terms of monitoring functional status.

For a certain size of population, these individual variations show up in PPS analysis of survival. At each level, there is an amount of significance, eg $p<0.001$, but also the confidence interval which catches the variations. We have just completed a study on a new tool, Prognostat, which uses PPS and other indicators, one of which is the Charlson Comorbidity Index. Interestingly, when all factors are considered, both single and multi-variate analysis, the co-morbidities "wash out' and had no impact of survival. So apart from determining which PPS level is appropriate for your patient, the stroke may have little impact.

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